PROGRAME

JÁCOME RATTON HIGH SCHOOL AUDITORIUM



OPENING

10:00

Moderation: Maria Abreu | ULS Santo António Sérgio Sousa | ULS Coimbra

Mayor of Tomar* Paulo Macedo | Director Jácome Ratton High School Inês Alves | ANDO

10:20 NATIONAL PLAN FOR RARE DISEASES & EUROPEAN REFERENCE NETWORK Maria do Céu Machado | National Plan For Rare Diseases - SNS Lorena Casareto | Rizzoli Orthopaedic Institute (Italy)

Paulo Gonçalves | RD-Portugal

11:10 RARE BAROMETER: A EUROPEAN PERSPECTIVE ON RARE CONDITIONS

Silvia Fittipaldi | Rizzoli Orthopaedic Institute (Italy)

11:40 NEUROSURGICAL COMPLICATIONS OF ACHONDROPLASIA Moise Danielpour | Cedars-Sinai, LA (USA)

12:10 CASE STUDY: CARDIORESPIRATORY REHABILITATION IN AN ADULT WITH PYCNODYSOSTOSIS Énio Pestana | Health Service of RAM, EPERAM

12:30 LUNCH

14:00 SESSION: RESEARCH AND THERAPEUTIC INNOVATION IN SKELETAL DYSPLASIA

> **HEALTH BEYOND HEIGHT** Will Charlton | Tyra (USA)

OVERVIEW OF BIOMARIN'S INVESTIGATIONAL RESEARCH PROGRAMS Angel Ayuga | BioMarin (Spain)

INFIGRATINIB: OUR PATH TO TODAY AND VISION FOR TOMORROW Michelle Norton | QED (USA)

INTRODUCTION TO ASCENDIS PHARMA AND TRANSCON TECHNOLOGY Veronica Diaz | Ascendis (Spain)

MARKET ACCESS AND EVALUATION OF HEALTH TECHNOLOGIES

Jalmira Mulchande | Xtrategical Pharma (for Kyowa Kirin)

14:00 DEALING WITH JOINT PAIN: PRACTICAL METHODS IN PHYSICAL MEDICINE AND REHABILITATION

PARALLEL Pedro Diogo Silva | Health Service of RAM, EPERAM Cláudia Aguiar | Health Service of RAM, EPERAM SESSION 1

ANDO ROOM

OPEN TALK: 15:00

PARALLEL

SESSION 2

THE POWER OF WORDS Moderation: Carolina Lemos | ANDO

ANDO ROOM

15:30 **VOSORITIDE EFFECTS: DATA INREAL WORLD CONTEXT** Inês Rua | ULS Coimbra

16:00 BIOPAUSE | COFFEE BREAK

16:30 ACADEMIC THESES IN SKELETAL DYSPLASIA: ANDO SCHOLARSHIP

> FIBROUS DYSPLASIA: OPTIMIZING FOLLOW-UP - Diogo Pontes | 2022 TRPV4: PHENOTYPIC SPECTRUM AND IMPACT ON QUALITY OF LIFE - Ana Correia | 2022 ACRODYSOSTOSIS: GENOTYPE-PHENOTYPE CORRELATION - André Abreu | 2024

16:50 ANDO SCHOLARSHIP 2025:

AWARDING OF CERTIFICATES TO WINNERS

Carolina Lemos | ANDO Moise Danielpour | Cedars-Sinai, LA (USA)

17:30 END OF DAY 1

Inês Alves | ANDO

18:00 GUIDED CULTURAL TOUR [PT/ENG]

TO THE HISTORICAL CENTER OF TOMAR WITH PROF. CARLOS TRINCÃO

20:00 CONGRESS DINNER [LODGE RESTAURANT]

Moderation: Carolina Lemos | ANDO Portugal

QUALITY OF LIFE FOR PARENTS OF CHILDREN AND 10:00 YOUNG PEOPLEWITH ACHONDROPLASIA

> Adekunle Adedeji | HAW Hamburg (Germany) Maria Salomão | HAW Hamburg (Germany)

10:25 FOOD LITERACY IN ADULTS WITH SKELETAL DYSPLASIA

Beatriz Guerra | ESSLei-Politécnico Leiria

EPIS | ENTREPRENEURS FOR SOCIAL INCLUSION: 10:45 **INCLUSIVE EMPLOYABILITY**

Susana Lavajo | EPIS

CHILDREN'S PARTICIPATION 10:45

IN RESEARCH PARALLEL Clara Sim-Sim | ANDO **SESSION 3**

ANDO ROOM

11:10 BIOPAUSE | COFFEE BREAK

11:40 SOCIAL POLICIES FOR INCLUSION

Gabriel Yamin | INN (Brazil)

12:15 CLINICAL APPROACH AND EARLY DIAGNOSIS CHALLENGES FOR SKELETAL DYSPLASIAS IN LUANDA

Frederico Tchimbenje | Hospital Municipal do Zango (Angola)

12:30 CLOSING SESSION: 10 YEARS OF ANDO | A

DECADE OF ACTION Inês Alves | ANDO



AUDITORIUM JÁCOME RATTON HIGH SCHOOL

> TOMAR **7,8 JUNE** 2025

COM O **APOIO**







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